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Disability Notes

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FROM THE ASSOCIATE COMMISSIONER:

Performance and accountability are cornerstones of our effort in the management of the Social Security Administration's (SSA) disability programs. Three million disability applications were received and processed last year. In addition over 1.1 million disability reconsideration, hearings and appeal cases were completed. Over 11 million individuals receive benefits from the disability programs administered by SSA. Processing current applications and reviewing and maintaining accurate information generated significant work for our offices at the local, state and national level. The Performance and Accountability Report for Fiscal Year 2001 contains a complete discussion of SSA's performance, accomplishments and goals in more detail. It can be reviewed on the web at: <http://www.ssa.gov/finance>.

Performance and accountability require that solid leadership be at the helm. We are fortunate to have such leadership in Martin H. Gerry as Deputy Commissioner of the Office of Disability and Income Security Programs. Mr. Gerry brings a wealth of personal and professional experiences to SSA and the disability community. Over his distinguish career Mr. Gerry has held key positions in both the public and private sector. His experiences range from key advisor to various Health Education and Welfare (HEW) Secretaries to Director of the Office of Civil Rights at HEW. Most recently he was Director of the Center for the Study of Family, Neighborhood and Community Policy. We want to welcome Mr. Gerry's to SSA and the disability programs.

At the threshold of the 21st century we are aware of and are working to meet the challenges of delivering the disability programs to the individuals who need them. Disability Notes will continue to perform its vital role of communicating with all those who are interested in the programs. In this issue you will find articles on events and activities, including the recently completed Second

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National Dialogue on SSI Childhood Disability, updates to the medical listings, Ticket to Work and Self-Sufficiency Program, new information available on the web and a wonderful human-interest story. I hope you find this issue interesting and helpful.

Ken Nibali

NEW LEADERSHIP AT SSA

On Wednesday, November 14, 2001, Jo Anne B. Barnhart was sworn in as the Commissioner of Social Security. "I truly believe that public service is a worthy and noble endeavor, and I thank every federal employee for deciding to make a career in government," said Commissioner Barnhart. "I am proud to head an agency blessed with so many dedicated and caring employees."

Commissioner Barnhart is a former SSA employee. She worked in the Office of Family Assistance from 1981 - 1986, first as Deputy Associate Commissioner and then as Associate Commissioner. She left to become minority staff director for the Senate Committee on Governmental Affairs. Most recently, she has served as a member of the Social Security Advisory Board, an independent body created to advise the Congress on Social Security issues and policies. Commissioner Barnhart served as a member of the Board for more than four years.

On Tuesday, February 7, 2002, Jim Lockhart was sworn in as the Deputy Commissioner of Social Security. Deputy Commissioner Lockhart served with distinction in the previous Bush administration as Chief Executive Officer of the Pension Benefit Guaranty Corporation. He has been a Director of the Association of Private Pensions and Welfare Plans (now the American Benefits Council) and has wide experience in financial consulting and investment banking. SSA is very fortunate that President Bush has chosen such talented and accomplished leaders to serve as Commissioner of Social Security and Deputy Commissioner.

SECOND NATIONAL DIALOGUE ON SSI CHILDHOOD DISABILITY

On March 14 and 15 the Office of Disability and the National Academy of Social Insurance (NASI) co-sponsored the second national conference on childhood disability under the Supplemental Security Income (SSI) program. The event was held at the Washington Court Hotel in Washington, DC.

This was a unique opportunity for families of children with disabilities to learn more about the SSI childhood disability program directly from administrators, researchers and policy analysts.

The first national childhood dialogue was held in March 2000, and was very well received. At that time, SSA was revising the interim childhood rules that

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had resulted from Public Law 104-193, the Personal Responsibility and Work Opportunity and Reconciliation Act of 1996. We published final rules in September 2000, and they became effective on January 2, 2001. The current conference provided an opportunity to share information and experience with the rules currently in use, as well as other issues of interest, such as making the transition from school to work and coordinating services for children with disabilities.

This year's conference co-chairs were Stephanie Smith Lee, National Down Syndrome Society, and Eileen P. Sweeney, Center on Budget and Policy Priorities. You can look for more information on the NASI web page, www.nasi.org.

NATIONAL YOUTH LEADERSHIP CONFERENCE

The National Youth Leadership Conference will be held in Washington, DC from July 26 - 29, 2002. The conference goals are to help prepare the next generation of disability community leaders and to develop recommendations for improving policies and services for young people with disabilities in the United States. This year's conference will focus on employment and career development. Approximately 70 young leaders will be chosen to participate.

The participants will: discover ways to advance leadership in the local community; learn leadership and career development skills; share ideas for improving the lives of young people with disabilities; network with past and future disability leaders; and make contacts that will spark new ideas and inspire them to work toward their dreams.

To learn more about this event call Elizabeth Guerrero at (800) 410-7069, ext. 110, or download an electronic version from the National Youth Leadership Network's Web site at www.nyln.org.

The Social Security Administration and a number of other federal agencies sponsor the National Youth Leadership Network.

SOCIAL SECURITY 2002 COST-OF LIVING ADJUSTMENT AND WORK INCENTIVE INCREASES

Social Security beneficiaries and Supplemental Security Income (SSI) recipients have received a 2.6 percent cost-of-living adjustment for 2002. This adjustment is based on the Consumer Price Index (CPI). But did you know that the substantial gainful activity (SGA) amount for the non-blind and blind and the trial work period (TWP) threshold services level are now also adjusted annually? The following are changes that became effective January 2002: SGA Non blind \$780 Blind \$1,300 TWP \$560 Also increased are the income amounts that will have no effect on eligibility or benefits for child Supplemental Security Income beneficiaries who are students. We increased the monthly amount from \$1,290 to \$1,320 and the yearly maximum from \$5,200 to \$5,340.

INITIAL DISABILITY DECISION MAKING PROCESS

In a prior issue of Disability Notes we discussed the definition of disability. We also discussed the role of SSA's field offices and the state's Disability Determination Services (DDS). In this article, we want to give a general overview of the decision making process used to decide if an adult is disabled. We will discuss the sequential evaluation process used to decide whether the adult applicant meets the definition of disability. The sequential evaluation process seeks to arrive at the decision by asking questions in a set order. If we can make a decision at a step, we stop. If we cannot, we go on to the next step.

1. Is the individual working? If the person is working and his or her earnings are SGA, the person generally cannot be considered disabled. A Social Security employee in a field office makes this decision. If the person is not working at SGA, the file goes to the DDS.
2. Is the condition(s) "severe"? A condition, or a combination of conditions, must interfere with basic work activities for a person to be considered disabled. If it does, the DDS will go to the next step. If it does not, the person is found not disabled.
3. Does the individual have an impairment that meets or equals one that is described in SSA's Listing of Impairments? SSA maintains a list of impairments for 14 major body systems for adults: musculoskeletal, special senses and speech, respiratory, cardiovascular, digestive, genito-urinary, hemic and lymphatic, skin, endocrine, multiple body, neurological, mental, neoplastic and immune. Impairments described in the listings are so severe that we presume that an individual whose impairment(s) meets a listing is disabled without considering age, education or work experience. If the person's condition(s) does not meet the criteria of one of the listings, the DDS decides if it is of equal severity to a listed impairment. If it is, the individual is found disabled. If the impairment(s) does not meet or equal a listing, we go to the next step. There are also separate listings for people who are under 18 years old.
4. Can the individual do the work he or she previously did? If the person's condition is severe but not at the same or equal severity as an impairment on the list (step 3 above), then the DDS must determine if it prevents the person from doing his or her past relevant work. If it does, the DDS goes to the next step. If it does not, the claim is denied.
5. Can the individual do any other type of work? In order to determine an individual's ability to do other work, the DDS considers the person's medical condition, age, education and work experience. If the DDS decides the person cannot do other work, the claim is approved. If the DDS decides that the person can do other work, the claim is denied.

If you want to get a detailed description of the process, we encourage you to refer to the disability regulations in subpart P of part 404 of Title 20 of the Code of Federal Regulations (CFR), for Social Security disability benefits and subpart I of part 416 for SSI. The basic regulations outlining the sequential evaluation

process for adults are at 20 CFR 404.1520 and 416.920. You can reach them through these links: http://www.ssa.gov/OP_Home/cfr20/404/404-1520.htm.
http://www.ssa.gov/OP_Home/cfr20/416/416-0920.htm.

The listings are only in Appendix 1 to subpart P of part 404, but they apply to SSI cases too. You can reach them at this link:
http://www.ssa.gov/OP_Home/cfr20/404/404-ap09.htm.

We also print the listings in a separate book, which includes a summary of the disability programs and our policies. Disability Evaluation Under Social Security, also called the Blue Book, is at this site:
<http://www.ssa.gov/disability/professionals/bluebook/>.

PUBLICATION OF PROPOSED RULES TO REVISE THREE BODY SYSTEMS IN THE LISTING OF IMPAIRMENTS

The listing of impairments contained in the SSA regulations is a part of the decision process used to decide whether an individual is disabled for purposes of the SSA disability programs. Revisions to the listings are made to reflect appropriate advances in medical knowledge, treatment and methods of evaluation.

We are proposing changes to the following 3 listings. You can review, comment on them and read public comments received, on our web site at www.ssa.gov. Scroll down the menu choices on the left to "Social Security Rules." Click on "Comments on Proposed Rules," then click on "Open Proposed Rulemakings" to select the regulation you wish to review.

HEMATOLOGICAL DISORDERS AND MALIGNANT NEOPLASTIC DISEASES

On November 27, 2001, we published a notice of proposed rulemaking in the Federal Register (66 FR 59306) that describes how we propose to revise the hematological disorders and malignant neoplastic diseases listings.

SKIN DISORDERS

On December 10, 2001, we published a notice of proposed rulemaking in the Federal Register (66 FR 63634) to revise the adult criteria we use to evaluate claims involving skin impairments.

DIGESTIVE DISORDERS

On November 14, 2001, we published a notice of proposed rulemaking in the Federal Register (66 FR 57009) to revise the criteria we use to evaluate claims involving digestive impairments.

PUBLICATION OF FINAL RULE FOR MUSCULOSKELETAL DISORDERS

On November 19, 2001, Social Security published final rules in the Federal Register (66 FR 58010) for determining disability in claims involving musculoskeletal disorders at step 3 of the sequential evaluation process--the listings step. The revised listings became effective February 19, 2002.

Although we published these regulations as final rules, we also asked the public for comments. We explained in the preamble that, although this is not our usual practice when we issue final rules, we recognized that there is significant public interest in the listings that we use to adjudicate musculoskeletal impairments. Impairments of the musculoskeletal system represent a high percentage of cases that we adjudicate under the listings. Requesting public comments on the changes we are making in this final rule, reflects our commitment that the listing reflect advances in medical knowledge with respect to the treatment and evaluation of musculoskeletal impairment. The comment period ended on January 18, 2002.

You can review the published regulations, as well as the public comments we received, on our web site, www.ssa.gov. Scroll down the menu choices on the left side to "Social Security Rules." Click on "Comments on Proposed Rules," then click on "Closed Proposed Rulemakings" to select this regulation.

VISUAL FIELD TESTING

We have expanded the number of tests that we can use to assess visual field loss. In the past, we have used Goldmann perimetry to assess visual field loss, but it has become increasingly difficult to get Goldmann test results because many doctors no longer use the Goldmann perimeter. However, on October 26, 2001, Humphrey Systems introduced a new "SSA Test Kinetic" which can be used on the automated perimeters that most doctors now are using. We have also introduced new guidelines for using variable threshold automated perimetry to assess visual field loss, including statutory blindness. Individuals may already have this type of test result in their medical record, which may mean that no additional testing will be needed. The new guidelines for assessing visual field loss will significantly improve customer service.

OVERCOMING THE CHALLENGE: A TRUE STORY

This story is about Dana and his willingness to seize opportunities currently available.

Has something happened to your online order? If you want to find out, you may find yourself communicating with Dana. As an email specialist for the Gap, Inc., Dana responds to customer e-mail throughout the day on a wide variety of issues, ranging from requests for details regarding marketing strategies and specific promotions to questions about online orders, store locations and product information. In his position, Dana handles electronic customer service

for the Gap, Old Navy and Banana Republic retail stores. He finds great satisfaction in his job. But there was a time when he did not know the joy of job satisfaction.

"I was receiving Supplemental Security Income," he recalls. Dana has a degenerative muscle disease known as spinal muscular atrophy. Because of this condition, he uses a wheelchair. The monthly payment he received from the Supplemental Security Income (SSI) program was enough to meet his basic needs. But Dana believed that he could be self-sufficient, and he did not want his disability to stand in the way.

With the help of the Social Security work incentives, Dana was able to give work a try. "My PASS [Plan for Achieving Self Support] is what allowed me to work," he explains. The PASS not only permitted Dana to work but also let him keep his SSI funds, which normally would have been at least partially offset by his wages. He used his SSI payment to meet his basic needs. He kept his PASS funds apart from his monthly SSI income by placing them in a separate bank account; the PASS account was only used to achieve the objective of the PASS.

"The goal of my PASS was to allow me to make a down payment on a van, which the Bureau of Vocational Rehabilitation modified for wheelchair transportation." With a reliable means of easily accessible transportation, Dana was able get to and from a job with greater ease. He was on the road to self-sufficiency.

"My advice to those who are considering going to work is to simply go for it," Dana says. "I am a firm believer in the idea that we all have some sort of skills we can contribute, regardless of any disability or obstacle that might seem to be in the way."

Dana remembers clearly the day that he began making a living on his own. "The feeling I got cashing that first paycheck was much sweeter having overcome greater challenges than most." He encourages anyone with a disability to take advantage of the work incentives. "Don't be afraid to try and to fail. After all, success would mean little if there wasn't failure along the way."

Dana's story is inspiring and Social Security hopes it sparks interest in the PASS program. Keep in mind that with a PASS you must have some money other than SSI to pay for the expenses. For many PASS participants it may be Social Security Disability Insurance benefits or Veterans Administration payments. You may also have money in a bank that you can use to pay for the expenses. We don't count the money used to pay for the approved PASS expenses in deciding SSI eligibility or payment amount.

If you are interested in learning more about PASS read this web page, <http://www.ssa.gov/work/ResourcesToolkit/pass.html>.

After you have looked this over, you may want to speak to one of the PASS specialists to ask more specific questions. Their toll free number can be found on the web page listed above.

TICKET TO WORK AND SELF-SUFFICIENCY PROGRAM -- REGULATIONS PUBLISHED AND FIRST TICKET ISSUED

Final regulations for the Ticket to Work and Self-Sufficiency Program (Ticket to Work Program) were published on December 28, 2001. SSA Commissioner Barnhart delivered the first tickets in New Castle, DE on February 5, 2002. David Nelms, President of Discover Financial Services, Discover Bank, joined Commissioner Barnhart to kick off the new program. Discover plays an important private sector role in helping people with disabilities return to work through its "BOOST" (Business Organization & Occupational Service Training) Program.

The Ticket to Work program will assist eligible Social Security and Supplemental Security Income recipients with disabilities to obtain, regain and maintain self-supporting employment by expanding their choice of employment, vocational rehabilitation and other support services. Under this program, SSA will no longer refer beneficiaries directly to state vocational rehabilitation (VR) agencies for rehabilitation services. Rather we will issue "tickets" to eligible beneficiaries, who will have the option of taking the ticket to an approved service provider of their choice, called an "employment network" (EN) or their state VR agency. Participation in the program is strictly voluntary-beneficiaries are not obligated to use the ticket once they receive it.

Once a beneficiary begins using the ticket for services, we will not initiate any continuing disability reviews (CDRs) as long as he or she is making progress toward the goal of reducing or eliminating his or her dependence on disability benefits. We will start by sending tickets to eligible beneficiaries with disabilities in the following 13 states: Arizona, Illinois, Oklahoma, Wisconsin, Colorado, Iowa, Oregon, Delaware, Massachusetts, South Carolina, Florida, New York and Vermont. We will be sending tickets to these beneficiaries over a five-month period in early 2002. We will continue the program by sending tickets to eligible beneficiaries with disabilities in the remaining states over the next 22 months. The schedule for the remaining states can be found at <http://www.ssa.gov/work/ResourcesToolkit/legisregQA.html#ticketstart>.

SSA has contracted with MAXIMUS, Inc., who will serve as the program manager to help us manage the Ticket to Work program. For more information on the Ticket to Work program, go to the Office of Employment Support Programs' work site, <http://www.ssa.gov/work>, or MAXIMUS' website, <http://www.yourtickettowork.com>. Information is also available from MAXIMUS at their toll-free telephone number, 1-866-968-7842 (1-866-YOUR TICKET), or their toll-free TDD line, 1-866-833-2967 (1-866-TDD2WORK).

Beneficiaries in the 13 States identified above who wish to receive their tickets

earlier in the five-month period should also contact MAXIMUS.

SOCIAL SECURITY UNVEILS NEW "REPRESENTING CLIENTS" WEB SITE

Claimants for disability benefits sometimes secure assistance from an attorney or other representative to pursue their claim. Recognizing the importance of timely and accurate information for those who represent claimants, SSA has developed a new web page to provide comprehensive information for representatives. The page provides links to key SSA regulatory and program resources. While the site is designed with the representative in mind, it can be accessed by anyone who is seeking information about SSA claims.

The website, located at www.ssa.gov/representation, contains information and links to the Social Security Handbook, Program Operations Manual System, and relevant sections of the Code of Federal Regulations. Specific information about the claimant representation process is provided by topic.

INCREASE IN THE REPRESENTATION FEE AGREEMENT

The Commissioner raised the maximum amount payable to representatives in the fee agreement process to \$5,300 for services provided to a claimant in pursuit of Social Security benefits. The limit is raised for fee agreements approved on or after February 1, 2002.

Representatives are paid 25% of past-due benefits. A cap on the amount payable of \$4,000 was established by legislation in 1990, which also provided the Commissioner the authority to increase the \$4,000 limit.

In the years since this limit was established, payments to beneficiaries have increased due to annual cost-of-living increases, while inflation has reduced the relative value of the \$4,000 maximum that can be paid to representatives.

The Social Security Act gives SSA the authority to approve fees for individuals representing Social Security claimants. In Social Security cases, when the representative is an attorney, SSA pays the fee directly to the attorney from the claimant's past-due benefits. In all other cases, SSA must approve the fee before a representative can charge a claimant for their services. Fees are most often authorized for representatives of claimants for disability benefits.

EDITOR'S NOTES:

In Search of your Ideas and Materials

This newsletter is your newsletter. We welcome your articles, letters to the editor, comments or suggestions for improvement. Many of your ideas have been included in recent issues.

Subscription

Disability Notes is free of charge to readers interested in the disability program. You can get all new issues on this web site. If you prefer to get a copy by E-mail or post office mail, please send your request to the Editor.

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